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Providing Access to Home Care for Disabled Children: Minnesota's Medicaid Model Waiver Program

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Synopsis

Home care programs for severely disabled, usually technology-dependent, children got a boost in 1981 when the Federal Government gave States

permission to use Medicaid to fund home care under the Medicaid model home- and community-based waiver (2176). The model waiver program was unique because it eliminated the bias toward hospitalization by waiving parental income and assets when determining eligibility for children cared for at home and by allowing Medicaid to cover needed home care services.

In 1985 Minnesota received Federal approval for the model waiver, and the results are detailed in this report. Although the waiver could provide funding for up to 50 children, after 2 years only 24 children had received approval. Stringent and complex eligibility criteria acted as barriers to accessing the model waiver. In addition, the interaction between the waiver and the State's health care system contributed to inconsistencies in eligibility. This interaction demonstrates the difficulty of administering publicly funded programs in the current health care environment.

Recommendations are made for adjusting criteria for eligibility in the waiver program. Unresolved problems facing technology-dependent children on home care programs are discussed.

IN THE EARLY 1980s, home care for high-risk, severely disabled children began to receive widespread attention as an option to long-term hospitalization. Home care was reported as less costly than hospitalization (1-7) and was believed to be more effective in promoting a child's mental, emotional, and physical health, although the effect on the child remains unsubstantiated (8).

By 1986, Minnesota and 13 other States offered funding for home care to disabled children through Medicaid home- and community-based model waivers (8). This program was unique because it removed parental income and assets as an eligibility consideration, thus permitting States to offer special services to a specified population normally not covered by Medicaid. It was expected that these

allowances would make home care more attainable for seriously disabled children.

When Minnesota sought approval for its waiver, the population specified for service was defined as chronically disabled children (9). However, the specified population could have been defined more narrowly as technology-dependent. All but one child receiving waiver funding were technology-dependent. Technology-dependent children are defined as those who require the use of medical technology to compensate for the loss of a normal vital body function, and who require substantial daily skilled nursing care to avert death or further disability (8). Meeting the needs of technology-dependent children poses a challenge to public policy because, while their numbers are small

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(estimated at between 2,300 and 17,000 nationwide) (8), their medical expenses are extremely high. According to one summary of literature, the average monthly charges for ventilator-dependent persons ranged from \$15,000 to \$51,517 for hospital care and from \$389 to \$7,425 for home care (8). Minnesota's Department of Human Services estimates average inpatient hospital charges for waiver-approved children to be \$25,430 per month. Monthly home care costs average \$10,182, with a range of \$943-\$20,835. These costs reflect charges made to the Medicaid model waiver. However, the model waiver, within certain cost containment considerations, covers special waiver services, such as case management, respite care, homemaker services, and so forth. In addition, the model waiver activates Medicaid. Medicaid in Minnesota is comprehensive and covers medical services, such as 24-hour nursing care, prescription drugs, medical equipment, inpatient and outpatient costs, and therapies. Minnesota's HMOs report monthly home care costs for technology-dependent persons from \$300 to \$20,000, with \$8,000 as the average (10). These costs reflect costs to HMOs only. Neither the HMO nor the waiver estimate includes indirect costs to the family. Two major indirect costs to the family using home care rather than hospital care are the provision of basic room and board and the provision of unpaid care by parents and volunteers (8). In fact, if a family does not assume this second cost and a child needs 24-hour nursing care at home, home care costs can equal hospital costs (8).

Not only are monthly costs of care high for technology-dependent children, but many are expected to survive long term, and hence the total

cost is potentially extremely high. The long-term nature of the prognosis not only affects cost concerns, but it influences humanitarian concern for these children who, without home care, might spend their lives in an institution.

The model waiver was created in response to these concerns and offered a means to fund home care. The government hoped not only to reduce expenses through this program but also to help disabled children avoid unnecessary institutionalization. Families with technology-dependent children hoped that with the waiver, funding of home care services would be more accessible. The purpose of this paper is to assess whether the waiver program did, in fact, make home care funding more accessible to disabled children in Minnesota.

Minnesota's Waiver

In 1981, Congress authorized model waivers through the Omnibus Budget Reconciliation Act, Section 2176 (Public Law 97-35) (10). In April 1985, Minnesota's Medicaid model home- and community-based waiver was approved by the U.S. Health Care Financing Administration on a 3-year renewal basis. Up to 50 children could be served on a model waiver. Minnesota set a maximum cost at \$13.8 million, funded by approximately 50 percent Federal dollars, 45 percent State dollars, and 5 percent county dollars. For a State to obtain approval of model waiver, it had to offer at least one home- and community-based service in addition to services included in the State's Medicaid plan. Minnesota opted to provide case management, homemaker services, respite care, environmental modification to the home, family counseling and training, and foster care as additional services to waiver-eligible children.

Waiver eligibility criteria. To be considered for the Minnesota waiver program, a child must meet all four eligibility criteria specified by Minnesota's Department of Human Services:

1. Child must be under age 21 (amended in October 1987 to under age 65).
2. Child must be eligible for Medicaid based on his or her own income and assets (not his or her family's income and assets).
3. Child must reside in or be at risk of inpatient hospitalization.
4. Child's home care costs must demonstrate a "savings to Medicaid."

Methods

We reviewed all State records, including applications and telephone and letter contacts, from April 1985 to February 1987 for the model waiver and tallied the outcome. We then analyzed the status (approved or denied) for those completing an application according to the program's four eligibility criteria. We were not able to analyze the telephone and letter records similarly. Because those contacts were informal and used for screening purposes, information was incomplete. However, for 46 percent of those informal records we were able to determine why an application was not pursued.

In addition, we interviewed administrators of the model waiver and 32 Minnesota families with technology-dependent children on home care programs. The administrators provided background information on the history and intricacies of the model waiver. The interviewed families included 16 families funded by model waiver and 16 families funded by private third-party payers. The family interviews were part of a larger study that will not be detailed in this paper, but their comments will be included to add to the understanding of how home care is funded in Minnesota.

Results

The outcome of the review of the 96 records in the files of the Home- and Community-Based Model Waiver is shown in table 1.

Of the 96 records, formal applications were completed for 48 children. For the remaining 48, information was requested by telephone or letter, but the application was not completed. Of these, 22 children were ineligible for model waiver because they were funded by private third-party payers, were not at risk for hospitalization, their medical condition had improved, or the child had died. For 26 records, there was insufficient information to determine the reason for the denial.

Of the 48 children with completed applications, 24 received approval, 19 were denied, and 5 had applications pending with either approval or denial as a possible outcome. The outcome of the analyses of the approved and denied applications according to the four eligibility criteria is detailed in table 2. Model waiver required that *all* eligibility criteria be met for approval.

Of 24 approved applications, 16 (66.7 percent) clearly met all criteria. The remaining 33.3 percent, even though approved, did not clearly meet all

Table 1. Status of 96 records of home- and community-based model waiver serving chronically ill children in Minnesota

Status	Number
Formal application made and reviewed	48
Approved	24
Currently in program	17
Currently not in program	5
Died	2
Moved out of State, continued to need funding	1
Improved, no longer needed waiver services	1
Received lawsuit settlement to cover funding needs	1
Never received services	2
Died	1
Received lawsuit settlement	1
Denied	19
Pending (application is being reviewed, may be denied or approved)	5
Phone and letter contacts only, no application made	48
Application process denied or not pursued	22
Child had insurance	14
Medicaid paid premiums for insurance coverage	2
Child's condition improved, no longer needed waiver	2
Child did not need in-hospital level care	2
Child died	2
Information was lacking, could not determine why application was not pursued or why application might have been denied	26

eligibility criteria because the child had insurance coverage (interpreted as not meeting the eligibility criterion of savings to Medicaid) or the child's risk of hospitalization was questionable, or both.

Of the 19 denied applications, 1 met all criteria. Three appeared to meet all criteria, and the remaining 15 (78.9 percent) either had insurance or the child's risk for hospitalization was questionable, or both. The reasons children received approval when all criteria were not met, while others were denied for not meeting all criteria, will be detailed in the discussion.

Discussion

Application issues. In the first 2 years of Minnesota's model waiver there were 96 inquiries, mostly by health professionals, on behalf of severely disabled children. The large number of inquiries about the waiver program at least reflects the interest in, and most likely the need for, a program funding home care. In addition, 65 of the records (43 applications and 22 telephone or letter contacts) contained third-party payer data. Of those 65 records, 51 percent of the children were covered by private

third-party payers. This number of inquiries for children covered by private third-party payers suggests private payers are not adequately covering their needs.

Although there were inquiries about receiving model waiver funding for 96 children, 75 percent of the children did not receive approval. The reasons for nonapproval are complex and are the focus of the discussion. However, before we explain reasons for denial, the approval group warrants further comment.

First, of 24 approvals, 5 (21 percent) did not stay in the model waiver program. One child improved and no longer needed funding at this high level, two children died and, of the remaining two, one moved out of Minnesota and one received a lawsuit settlement. The outcomes for the latter two children suggest that, while some children leave waiver, they continue to have high funding needs, which will be covered by other public programs or private sources. In other words, leaving the State waiver did not diminish the need for funding, but rather represented a shift in funding responsibility.

Second, in the first 2 years of the program two approved children were never funded because a settled lawsuit paid for one child's home care services, and the other child died. From review of these two records, we believe that the children's medical instability affected their ability to access the waiver quickly. We do not believe that the lengthy application process, in these two cases, had a bearing on their receiving approval but no funding. However, the application process is lengthy and involved and may act as a barrier, especially for those children whose eligibility is questionable.

The application contains 25 pages and requires a detailed accounting of required services, supplies, and home modifications; assessments of the child's family support and medical condition; demographic and financial data; a list of professional contacts; and cost comparisons. The application is usually completed by a health professional, and it must be reviewed at an interdisciplinary team meeting which includes professionals and parents. Portions of the application form must be resubmitted every 6 months as part of the reassessment process.

Although the application process generated some complaints from parents and health professionals, we believe the details in the application are required to monitor costs and the adequacy of the child's care plan ("Evaluation of Minnesota Home and Community-Based Model Waiver for Chronically Ill Children" by B. J. Leonard, unpublished

report to the Minnesota Department of Health and Human Services, St. Paul, 1987).

One to 12 months was the range from the time that a family first heard of the waiver program until approval. Half of the applications took 3 months or less. The longer approval times occurred in the early stages of the program and included some who heard of the waiver prior to its approval by the Federal Government. (Source of these data is the unpublished evaluation report just mentioned.)

If model waiver were the only program existing, the complexity of the application might seem more acceptable. However, similar programs exist, and each is accessed separately. It is the complexity of the larger health care system's interaction with the model waiver that creates barriers for health professionals and parents when they try to access funding for disabled children.

Other resources. Eligibility for the model waiver program is complex because decisions are guided by many of the same principles that guide the Medicaid program upon which the waiver is based. A major Medicaid principle is that Medicaid must be considered the payer of last resort. In other words, other resources must be tapped first. The model waiver goes one step past Medicaid and is considered the payer of last resort after Medicaid. Therefore, if a technology-dependent child's needs can be met by Medicaid (which in Minnesota is very comprehensive), the model waiver would not be accessed. Model waiver covers not only Medicaid services but special services (case management, homemaker, home modifications, and so forth). Not all families need or want these extra services; therefore, Medicaid might adequately meet the child's needs, and eligibility for the model waiver would be denied. For the one child who met all eligibility criteria and the three who possibly met all criteria (table 2), the determination was made that Medicaid would cover all the services the child needed. Once the determination was made to access Medicaid instead of waiver, it did not matter whether the child was at risk for hospitalization because that is not an eligibility criterion of Medicaid. Thus, the information was not obtained.

As mentioned previously, the model waiver is just one program that helps families care for their disabled children at home. In Minnesota, in addition to the State's Medicaid program and model waiver, there are several other special Medicaid programs which might benefit disabled children, such as the Children's Home Care Option

Table 2. Comparison of eligibility criteria to approved and denied model waiver applications for chronically ill children in Minnesota

Outcome	Approved		Denied	
	Total (N = 24)	Percent	Total (N = 19)	Percent
Met all criteria	16	66.7	1	5.3
Possibly met all criteria (information on risk for hospitalization missing)	0	0	3	15.8
Did not meet 1 or more criteria	8	33.3	15	78.9
Had insurance (could not show savings to Medicaid)	3	...	7	...
Risk for hospitalization questionable	2	...	2	...
Had insurance and risk for hospitalization questionable	3	...	6	...

(TEFRA, Section 134), the home- and community-based services waiver for persons with mental retardation or other related conditions (MR waiver), and the community alternative for disabled individuals (CADI). Each program has its own eligibility criteria and funding limits. For example, children with insurance coverage are eligible for the MR waiver, but it funds a much lower average daily amount. Although most of the children for whom the model waiver was sought have needs in excess of funding allowances for the MR waiver, sometimes there is an overlap in diagnoses and needs for the two programs. For example, a particular child may be better served by the MR waiver, but because the MR waiver has a waiting list, an advocate may try to access the model waiver. This is but one example of how the existence of other resources affects decision making. Each public program began as an attempt to fill a gap in the health care system by helping a specified population. The programs do fulfill that goal, but they also increase the complexity and confusion in the total system.

The model waiver was also created to fill a gap in the health care system. Prior to the model waiver, there was no public program to support the funding of home care for children with very high medical expenses who would be institutionalized without such a program. The model waiver was created to achieve two stated goals: (a) to reduce expenses (for Medicaid), and (b) to avoid unnecessary institutionalization of children.

Minnesota's model waiver was written by a group of professionals dedicated to the betterment of these very fragile children. The avoidance of institutionalization was deemed highly desirable. It was in that environment, early in the program's history, that insured children were approved for model waiver because their insurers either refused to fund home care or did so at an inadequate level. To deinstitutionalize these children, the State sup-

ported or supplemented the funding of their home care programs.

However, as the number of insured children seeking waiver approval increased, the State tightened the interpretation of the "savings to Medicaid" criterion to mean that children with in-hospital insurance coverage would be denied waiver unless Medicaid was responsible for a portion of the in-hospital charges. This interpretation was in response to the State's fear that private third-party payers might use the waiver program as a dumping ground for those with high costs.

While it is still possible that an inadequately insured child could receive model waiver, no one has. The reason is that in-hospital coverage would need to be so grossly inadequate that Medicaid would be responsible for part of the in-hospital charges (unpublished evaluation report by Leonard). For example, if a child had insurance and Medicaid and Medicaid was responsible for \$10 per day in-hospital charges, waiver would only pay \$10 per day for home care.

Of the six children who were approved even though insured, four had indemnity coverage and two belonged to HMOs. Families were encouraged to pursue lawsuits or negotiations with their private third-party payer for total or increased home care coverage, but the State did not assist them or deny eligibility if the family did not follow through. Later, insured families were denied model waiver outright and had to pursue lawsuits or negotiations on their own. From our interviews, we learned that some families with private third-party payers have managed to negotiate acceptable levels of home care services while others continue to feel dissatisfied with services. In effect, each family must solve this problem on its own.

This decision to deny the waiver to insured children is controversial. The Minnesota Council of HMOs believes the interpretation is incorrect; however, all appeals have upheld the State (10).

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The decision to deny waiver to children with private third-party payers has meant families without adequate private coverage must decide how to handle the limitations placed by their policy, for example, by going without a particular service, using savings or income, requesting others to volunteer care hours or funds, and so forth. Ironically, because coverage for children on model waiver is comprehensive and many private third-party payments are not adequate to meet the family needs, the State has created a two-tiered home care system, with children in the model waiver program often receiving the superior package.

Although the model waiver was created to make home care more accessible, it has not been able to fill this gap completely. With the State's new interpretation of the savings to Medicaid criterion, children who are inadequately insured, children whose insurer will cover hospitalization and not home care, and those whose home care costs are in excess of hospitalization costs are all ineligible for waiver funding. For the last group mentioned, the State resolved the dilemma for one child by reducing services, thus satisfying the savings to Medicaid criterion. One way to reduce costs is to have parents accept more care hours or use LPNs or homemakers in lieu of RNs. This may be an acceptable solution, but there is no research that evaluates the difference in the quality of home care provided by parents, paraprofessionals, or professionals (8). However, several qualitative studies (11-13) and one unpublished quantitative study ("Psychological Distress of Parents Caring for Technology-Dependent Children at Home" by B. J. Leonard, J. B. Brust, and J. T. Patterson)

reported high stress levels for families with children on home care programs. We are concerned that reduced services will increase parental stress levels over the long term and reduce parental ability to cope, compromising family functions and ultimately, the chronically ill child's well-being.

Eligibility issues. While the savings to Medicaid criterion poses the main barrier to accessing the model waiver, the child's need to reside in or be at risk for hospitalization is one other criterion that has been problematic to interpret. In addition, a State requirement (not a Federal criterion) that parents must desire and be able to care for their child poses additional concern.

At risk for hospitalization. Approving this criterion is the physician's decision. However, when we reviewed applications for the waiver, the physician's decision was sometimes unclear because some physicians checked two mutually exclusive care levels on the application. Perhaps the physician did not understand the difference in care levels for children or he or she was aware of alternative placements, in other words, what other resources existed. For example, a physician may have believed a child required intermediate care, but if space was not available, both intermediate and hospital placements were indicated on the application to avoid denial.

In a further attempt to analyze the application of the "risk for hospitalization" criterion, we compared children's needs for medical equipment using the Office of Technology Assessment's (OTA) definition. According to OTA's criteria, the first three of four technology-dependent groups are likely to be at risk for long-term hospitalization: (a) those dependent daily on mechanical ventilators, (b) those requiring prolonged intravenous administration of nutritional substances or drugs, and (c) those dependent on other device-based respiratory or nutritional support, including tracheostomy, suctioning, oxygen support, or tube feeding. The fourth technology-dependent group includes children on apnea monitors, renal dialysis, urinary catheters, and colostomy bags. These children in the fourth group are considered less susceptible to long-term hospitalization (8).

Of the five approved children (table 2) who had questionable care levels, one was on a ventilator (considered at "highest" risk for hospitalization), one needed intravenous nutrition, and two were on tube feeding. The fifth child was not technology-dependent, but was dying and was totally depen-

dent for care. Of eight denied children (table 2) who had questionable care levels, four had tracheostomies, gastrostomies, or required suctioning; one used a catheter; and information regarding medical equipment was lacking for the remaining three children. The eight denied were severely disabled children who had diagnoses similar to the children who were approved, including coma, quadriplegia, degenerative neurosystem diseases, and multiple congenital anomalies. We feel these findings indicate that a more standardized method should be used when determining care levels.

Parental desire and ability to care for the child. This requirement is considered met when parents indicate on the waiver application their desire and ability to care for their child. Although screening by the interdisciplinary team takes place in the hospital, we know of no waiver application denied because of the parents' inability to care for the child. Our review of records called into question how discharge teams screen parents' ability and desire to have their child home. For example, the records indicated that home care was considered for children whose parents were reported by professionals to be chemically dependent, mentally ill, mentally retarded, or chronically ill. Although these families may be able to handle the responsibility, they may need additional support, which increases funding needs. Our concern is that parents will be assessed as being more able than they really are because medical costs can be saved by sending the child home.

Although all parents on waiver are purported to want home care, some families may have desired home care because they felt there were no other alternatives. When 16 waiver families were asked if they believed they had other placement options besides home, 44 percent responded "no" (unpublished evaluation report by Leonard). In reality, most families did not have other options.

Theoretically, other care options beside home and acute hospital care exist for technology-dependent children. These options include transitional wards in hospitals, rehabilitation or chronic care hospitals, pediatric skilled nursing facilities, specialized community group care (8), and foster care. However, in Minnesota, these other placements are limited or nonexistent, thus narrowing the choice between home and hospital (10). And although private third-party payers' contracts vary, most save money by placing a child at home. Public funders are mandated to show savings by sending children home. Therefore, there is consid-

erable incentive for private and public payers to encourage home care rather than hospital care. Some parents verified our concern that home care would emerge as the only option by reporting that they were being pressured to take their children home from the hospital before they felt ready.

Records also revealed informal notes of parental abuse and neglect of the ill child or siblings both before and during the waiver approval process. Because of the financial pressures to send children home, we believe meeting this requirement necessitates more scrutiny than merely ascertaining the parents' consent and subjective opinions of team members when serious questions about parental ability have been raised.

Waiver was created to fill a gap in the health care system. While waiver has been able to help a small number of children, the difficulties the program has had in determining eligibility mirror the larger issues society must face. Financial, ethical, and humanitarian issues must be continually weighed for these fragile children.

Conclusions and Recommendations

Prior to this decade, medically fragile children remained in hospitals. A shift in thinking, which began in the early 1980s, gave rise to the possibility, and then the reality, of home care. In Minnesota, as the end of the decade approaches, home care has replaced hospital care as the placement of choice. We suggest that professionals reexamine this stance. Without adequate funding for home care, quality and safety issues are of concern. And without a statewide system of care for these children, a patchwork system results, causing needless frustration and confusion for parents and professionals and gaps in funding distribution. Waiver, which is considered a model program by many, was not totally able to resolve the problems that parents hoped it would address; that is, to make home care funding more accessible. Of 96 needy children, only 24 were able to receive approval. Of the remaining 72, it appears from the records that they were counseled about other programs or services. Whether they received as much help as they needed could not be determined in this study.

Although Minnesota has tried to solve problems faced by families with technology-dependent children, a number of issues remain. We suggest that when States consider developing a home care funding program for its children, the following actions should be taken:

'In Minnesota, as the end of the decade approaches, home care has replaced hospital care as the placement of choice. We suggest that professionals reexamine this stance. Without adequate funding for home care, quality and safety issues are of concern.'

1. Define and determine the numbers and types of children needing home care.

2. Determine what funding sources exist and how they can be coordinated to adequately fund home care. For example, a risk pool for private and public payers is often cited as a possible solution to cover funding in Minnesota (10).

3. Develop a system of both short- and long-term placements for technology-dependent children.

4. Set statewide home care standards that must be met before any child is sent home.

5. Carefully review eligibility criteria to ensure accuracy of the measurements and consistency with which they are applied. One eligibility criterion and one State regulation could be strengthened as follows.

Risk for hospitalization. We suggest standardizing this criterion by rating the risk for hospitalization based (a) on the child's equipment needs as outlined by the Office of Technology Assessment (8) and (b) by the child's level of dependency. The level of dependency would indicate the amount of skilled nursing care each child needs. Although technology-dependent children in the first three groups as defined by OTA are considered at greater risk for hospitalization, some very disabled children are not technology dependent, yet they need skilled nursing care.

Parental desire and ability to care for the child. This requirement would be strengthened if, at discharge, parents were rated on their ability to care for their child (8, 14-16). A list of basic requirements could be standardized. Suggested requirements are that parents demonstrate permanent residence in the home, display an ability to use equipment and understand its physiological effects on the child, and be able to care for the child for a specified number of hours per day after an initial

start-up period. The number of hours should be reasonable and consider the parents' basic needs for work, sleep, and recreation and alternative care available when parents are absent. We offer the recommendation of parental care to counter problems that some parents have had in bonding to a child when they provide no care. These requirements would provide some assurance that parents truly desire and are able to care for their child at home.

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